

## Reflections on Mom's Walk Home

By Kim Cain (Family of Patients Sharon Sampson and Rita Drew)

In 2012, we encountered a storm filled with emotions, challenges, struggles—dotted with a few sweet moments. This storm was our first care giving experience as my mother was sent home with us to live out her final days. If ever there was a time we felt inadequate, uncertain and uneasy, it was then. There were no words...no fixes, just the reality of how fragile life is.

The first few days of her homecoming were bumpy, to say the least. In those few days, my mother managed to sleep just a handful of hours, and we were not coping too well with the demands of her care. It wasn't until a case manager showed up and took one look at us and knew something had to change. Although she was there to see our loved one, she saw us, the family! We don't know if she saw the stress, fatigue, or the fear in our eyes of feeling inadequate for the task at hand, but she offered hope. With a small adjustment in medication, she felt confident our care experience of the first days was not going to be the norm—it was going to get better. With just a few words of hope, she had us thinking, "Maybe we can do this impossible thing!" I tell you this as a reminder - Your encouraging words have so much weight!

Every time you showed up at the door, we felt relief! Your presence quieted our angst—even if it was just for a little while. Your time in our home meant we didn't have to shoulder the responsibility of our loved one's care alone. Your experience and empathy heartened us for days ahead, recharged us when our confidence ebbed, and assured us when guilted by our own emotions. We were traveling a seemingly unnavigable trail. By simply doing what you do, you showed us the way and emboldened us to continue. Even when the storm raged, your presence gave us rest. Thank you!

We found caring for our loved one very challenging! There were times we couldn't discern what was going on with my mom, or how to deal with her ever changing needs. Was her behavior a medication side effect... grief due to a loss of independence, or was the fear of death too much to bear? The difficulty and demands of her care were so challenging that, at times, it felt detrimental to the welfare of our household. Sometimes we felt cornered by the circumstances of being my mother's only resource. As we wearied of the care giving, we felt we were at our limit, and we called for a care meeting with the doctor. With understanding and compassion, he listened to us, and seeing our needs, he assured us he was attuned to the needs of my mother and committed to her whole wellbeing and comfort. He prescribed some changes, weaning her off a steroid that appeared to be making mom hyper-aggressive, and re-established her mood enhancing and diabetic medications. Those adjustments took us from "This is unbearable" to "Maybe we can continue with this impossible journey!"

I remember calling the hospice line, whenever feeling uncertain about something with my mom's care. Often, when calling for help to address the situation, the nurse on the other end of the phone would hear something in my voice—perhaps some apprehension, and offer to come over. This happened not only with Mom, but also with my grandmother whom we cared for in 2017. I always felt relief you were coming! On May 7th, which would be Mom's last day with us, she was having difficulty breathing. I tended to the situation as you had

instructed. But on this day, the issue would not resolve. My mother's anxiety was growing and so was mine. I ran to the garage to call you so Mom could not hear the panic in my voice. I was on and off the line with you for the next four hours. I had no problem carrying out your instructions, but I became increasingly aware my mother needed the assurance of your presence, the professional in her room. I appreciated your calm, reassuring voice on the other end of the line but, for my mom, your physical presence did what I and the morphine could not—and her breathing was no longer labored.

Within an hour or so of the nurse leaving, I heard an unfamiliar sound. I realized something was dreadfully wrong. Our nurse, Stellena lived in the neighboring subdivision and I called your office and asked if you would send her over. I remember her coming through the bedroom door and seeing my mom. Tears brimmed in her eyes as she let me know I needed to call my husband back home and to call other family. Her tears let me know Mom was not just another cancer patient, not another block in her scheduled day, but a person—a person who had also touched her life.

We've heard about Sherpas, a group of people highly regarded in the climbing community, who have a biological composition that makes them well-suited for high altitudes. They guide climbers to do what most consider impossible. In the same way, your caring and compassionate hearts, make you well suited to guide others through the tough peaks and arduous passageways of their caregiving journey. You are extraordinary human beings who do extraordinary work! We wanted to be a part of celebrating you, to encourage you not to grow weary in the good that you do! Your humanity, expertise, and encouragement helped us to walk our loved one home and we are forever grateful! Because of you, we made it through our storm, and learned to appreciate what was good in the journey.